

POPINVITED: ID# 101031

Title:

A Qualitative Study: Caregiver Experience of Dementia

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ACCEPTED

Session Title:

Rising Stars of Research and Scholarship Invited Student Posters

Slot:

RS PST1: Sunday, 17 November 2019: 11:45 AM-12:15 PM

Applicable Category:

Students

Keywords:

adult day center, caregiver resilience and dementia

References:

Alzheimer's Association. (2018). Alzheimer's disease facts and figures. Retrieved from https://www.alz.org/documents_custom/2017-facts-and-figures.pdf.

Anand, K., Dhikav, V., Sachdeva, A. & Mishra, P. (2016). Perceived caregiver stress in Alzheimer's disease and mild cognitive impairment: A case control study. *Annals of Indian Academy of Neurology*, 19(1), 58-69.

Czekanski, K. (2017). The experience of transitioning to a caregiving role for a family member with Alzheimer's disease or related dementia. *American Journal of Nursing*, 117(9), 24-32.

Roberts, E., & Struckmeyer, K. M. (2018). The impact of respite programming on caregiver resilience in dementia care: A qualitative examination of family caregiver perspectives. *The Journal of Health Care Organization, Provision, and Financing*; 55,1-11. doi:10.1177/004695801775150

Warchol-Biedermann, K., Mojs, E., Gregersen, R., Maibom, K., Milla´n-Calenti, J., & Maseda (2014). What causes grief in dementia caregivers? *Archives of Gerontology and Geriatrics*; 59, 462-467.
<http://dx.doi.org/10.1016/j.archger.2014.05.013> 0167-4943/

World Health Organization. (2018). Dementia. Retrieved from <http://www.who.int/news-room/fact-sheets/detail/dementia>

Abstract Summary:

The caregivers of individuals with dementia experience burdens associated with emotional, physical, and financial repercussions for themselves as well as their loved ones. Using respite services promotes resiliency in the caregivers and supports a healthier mental, emotional, social, and physical well-being.

Content Outline:

1. Background and significance
2. Incidence of Dementia
3. Purpose
4. Theoretical Framework
 1. Caregiver Resilience
 2. Long term Role Changes
5. Methods
 1. Focus Groups
 2. Demographic Data
 3. Audio Recorded and Transcribed
6. Results
 1. Participants
 2. Themes
7. Conclusions
 1. Benefits
 2. Future Research

Topic Selection:

Rising Stars of Research and Scholarship Invited Student Posters (25201)

Abstract Text:

Purpose and Background/Significance: The incidence of dementia is growing worldwide and affects about 50 million people (World Health Organization, 2018). In the U.S., dementia affects an estimated 5.7 million Americans, and this number is expected to rise to nearly 14 million by 2050 (Alzheimer's Association, 2018). Dementia has ramifications for those affected as well as their loved ones (Czekanski, 2017). Approximately 70-80% of people with dementia reside with a caregiver (Roberts & Struckmeyer, 2018). Caring for a loved one is associated with emotional, physical, and financial repercussions (Warchol-Biedermann et al., 2014). Because of these repercussions, caregiver respite is one factor that may sustain resilience over the continuum of care for family members caring for an individual with dementia (Roberts & Struckmeyer, 2018). The objectives of this qualitative study are to assess the physical, emotional, and psychological effects of being a caregiver for someone with dementia and the impact of using an adult day service.

Theoretical/Conceptual Framework: Caregiver resilience is the successful use of coping strategies that emphasize the perspective of resilience rather than burden (Roberts & Struckmeyer, 2018). Resilience can be defined as being able to maintain normal or enhanced functioning during stressful caregiving experiences. Fitting with the conceptualization of resilience, caregivers experience subtle but long-term role changes, both physical and emotional (Roberts & Struckmeyer).

Method: The sample consisted of caregivers of people who attend an adult day service center; they were invited to participate during support sessions offered by the facility. Undergraduate nursing research assistants conducted two focus groups of 5 participants each to assess the caregivers' experiences with their loved one. Data were collected through a series of structured, open-ended questions. Each session was audio recorded and transcribed verbatim for analysis. No attempt was made to connect voices with individual identities. All recordings and transcripts will be destroyed after dissemination of the data. As a thank you, each participant received a \$25.00 gift card to a local merchandise store and was provided refreshments during the focus groups.

Results: Participants included 6 males and 4 females. The participants were white (90%) and Hispanic (10%) and ranged in age from 46-72 ($M = 65$, $SD = 10.58$). Half of the caregivers were employed outside of the home. The participants reported providing care an average of 6.1 years ($SD = 6.0$) and using the adult day service an average of 1.8 years ($SD = 0.98$). The purpose for using the service included multiple reasons (40%) such as shopping, exercising, and socializing; benefiting the client (40%); providing respite (10%); and working (10%). Four themes emerged from the data: most common emotional responses, benefits of adult day service, overall impact on daily life, and caregiver social isolation. The first theme "most common emotional responses" included participants' feelings of grief, denial, frustration, and despair. When participants described the "benefits of an adult day service", they felt grateful for the security and peace of mind provided. It gave them time to benefit their lives and helped promote resilience. Another theme "overwhelming impact on daily life" was the expression of role overload that changed the way they lived their daily lives. Not only did it impact them, but their family members as well. The last theme "caregiver social isolation" was a main concern expressed by participants in which

they expressed feeling disconnected from their lives, friends, and social connections. Some even expressed feelings of being a burden to others.

Conclusion: Results demonstrated that respite services, such as adult day centers, provide caregivers opportunities for self-care, the ability to perform daily tasks, and a decrease in emotional burden. Using respite services promotes resiliency (Roberts & Struckmeyer, 2018), decreases burden in caregivers (Anand, Dhikav, Sachdeva, & Mishra, 2016), and supports a healthier mental, emotional, social, and physical well-being. Future research should include the investigation of barriers that caregivers face when learning about an adult day center and should explore the impact of adult day services on the person with dementia.